

TOWARD A DEFINITION OF INFORMATION THERAPY

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ABSTRACT

In these days of healthcare reform, there is an increasing need to control the costs of medical care. Preventive medical care can help by providing information to the patient, not only for illnesses, but for prevention and wellness. "Information Therapy" is a new term for supplying patients with health information, enabling them to make informed decisions about their health and care, participate in their own well-being, and thus decrease the utilization of healthcare resources. The formal definition for Information Therapy is presented and the basis for defining it lies in bibliotherapy, patient education, consumer health trends, patient's rights, and the Freedom of Information Act. The parameters and coverage of Information Therapy are discussed, the roles that Information Therapy can play in healthcare are explored, and the dual nature of its goals is presented. Barriers to its implementation are listed, however, the electronic age with its information superhighways is expected to provide a unique delivery system for Information Therapy.

INTRODUCTION

In a 1992 article in JAMA, Lindner introduced the phrase "information therapy," although she gave no formal definition for it[1]. The focus of her article concerned the use of the medical library by the public, and she stated that "every scrap of information leading patients in the direction of discovering more about their disease becomes 'information therapy' ". This paper presents as a formal definition that Information Therapy is "the therapeutic provision of information to people for the amelioration of physical and mental health and well-being." To support this definition, various aspects of information and its provision will be explored, along with the roles Information Therapy can play in healthcare, and the goals it should strive for.

THE ROOTS OF INFORMATION THERAPY

Bibliotherapy

The basis for beginning to define Information Therapy starts with a look at bibliotherapy. The term *biblio* means book, and therapy is derived from *therapeia*,

which means to serve and to help medically. Sadie P. Delaney, one of the early practitioners of bibliotherapy, defined bibliotherapy in 1938 as "the treatment of a patient through selected reading"[2]. Bibliotherapy has been called "helping with books"[3], "the use of selected reading materials as therapeutic adjuvant in medicine and in psychiatry" and "the use of reading as an ameliorative adjunct to therapy"[4]. Bibliotherapy is generally regarded as directed reading with a therapeutic dialogue or interaction between the patient and a facilitator, often a librarian, who has received special training. The idea of bibliotherapy goes back to the early Greeks, who recognized the healing value of reading and placed inscriptions over their library entrances that meant "place of healing for the soul." In addition, as early as the 1800s, Dr. Benjamin Rush recommended the Bible as therapeutic reading. Just as reading can have a therapeutic benefit in bibliotherapy, the possession of information can have a therapeutic effect on mental and physical health and well-being in Information Therapy, and its definition should contain some reference to the therapeutic value of information.

Patient Education

Another aspect of Information Therapy can be derived from a look at patient education. A 1984 definition by Johnson states that patient education is "designed to assist patients to cope voluntarily with the immediate crisis response to their diagnosis, with long-term adjustments, and with symptoms; to gain needed information about sources of prevention, diagnosis, and care; and to develop needed skills, knowledge, and attitudes to maintain or regain health status." [5] Green defines health education more broadly than patient education, stating that it is "a combination of learning experiences designed to predispose, enable, and reinforce" behavior in the general public.[6] Therefore, the term 'patient education' is seen to be too restrictive, and should be replaced with the term 'Information Therapy'. Squyres makes a differentiation between health education and health information, in that, health education is designed to teach and change behavior, whereas health information is simply meant to be informing. In addition, his definition of health education encompasses both patient education for diseases and health promotion for wellness and prevention.[7] These definitions supply three central tenets that should be included in the definition of

Information Therapy. The first idea is the provision of information, regardless of whether it is intended simply to inform or whether it is meant to change behavior. The second tenet is that Information Therapy can be centered either on the patient or directed toward the general public. Last, Information Therapy should not be limited to information directed toward a specific disease, but could also include information of a preventive nature. In this way, the aim of Information Therapy is to increase the knowledge of the general public and to create a sense of responsibility in patients for preserving and maintaining their own wellness. A key word seen in one of the definitions of patient education is enable, which also means to empower. By providing patients with information, we are enabling or empowering them to take an active role in their own healthcare. By utilizing information received through Information Therapy, people can provide some self-care and accept responsibility for their health and well-being.

Consumer Trends

The current consumer trends provide another basis for defining Information Therapy. The best seller *Megatrends*, [8] describes an increase in societal pressure for health information as people are shifting from institutional reliance to self-reliance. In order for health conscious consumers to be self-reliant, they must be provided with information. The new Information Age with its information "super highways", should provide consumers with endless access to massive amounts of health information. Also emerging is a new field, called Consumer Health Informatics, which studies the development and implementation of computer and communication systems designed to be used by consumers themselves. This growing trend of individuals who are actively seeking information about health is discussed by Ferguson [9]. The three categories of health consumers that he describes are: passive patients, concerned patients and health-active, health-responsible patients. Passive patients are individuals who feel that there is nothing they can do to manage their illness. An example of this type of consumer is the cancer patient who gives up without a fight. These patients rarely seek information about their condition, or how to manage it. Concerned patients are individuals who occasionally ask questions, but simply do whatever their doctor recommends. These patients will seek information from sources other than their doctor, but only if they feel that their physician approves. Health-active, health-responsible patients are individuals who are motivated to play active roles in their own care. They will actively seek information from a variety of sources. Ferguson states that "these are the most enthusiastic and tireless seekers of health information." (p.10) They refuse to relinquish control,

and demand to play a role in the decisions that have to do with their care. He estimates that by the year 2000, one in four consumers will be active information seekers. These people will benefit most from Information Therapy.

Patient's Rights

Another basis for defining information therapy is the patient's right to be informed. Recognizing this need, the American Hospital Association developed *A Patient's Bill of Rights* in 1972. Of this list of rights, half relate to receiving information about diagnosis, prognosis, treatment, medical procedures, personnel, or the hospital itself. [10] "Informed consent" requires that patients be provided with the necessary information to make decisions about their health care and involves a written legal document verifying that the patient has received information and has had the opportunity to ask and receive answers to any questions. Hospitals are adamant about fulfilling these moral obligations, but the obligation to provide information to people should extend beyond healthcare providers, and constitutes a fundamental basis for Information Therapy.

Freedom of Information Act

The roots of Information Therapy must also lie in the Freedom of Information Act, which guarantees that people have access to information. To deny a patient health information would be a breach of this Act, and would be a limitation of their right to know. Hafner states that in democratic societies today, "it is well established that the individual, as a patient, family member, or concerned consumer, is entitled to free and unrestricted access to information." [11] Legal obligations to provide information are well established in other consumer arenas such as lending laws, and the labeling of food products, toys, and the provision of pharmaceutical information and interactions to patients. Therefore, a moral as well as legal obligation to provide health information to consumers through Information Therapy is not an unreasonable concept.

THE ROLES OF INFORMATION THERAPY

Many terms have been used for the delivery of information to a patient concerning their health: health education, health information, patient education, patient teaching, patient counselling, and now, a new term "Information Therapy". The use of these differing terms can be confusing and in some cases inappropriate. However, the term "information therapy" appears to be the most descriptive, the richest in possible meanings, and the broadest in scope. Although this term was originally and exclusively used by Lindner [1], a 1993 symposium concerning "Information Therapy" was held

in New York, where the meanings and uses of information therapy were discussed, and publication of the proceedings from this symposium should help to clarify and advance this term.[12]

Brenda Dervin, a communications specialist, sees information as anything a person finds informing.[13] Individuals cope by trying to make sense of their world, and drawing upon resources available, such as what they have heard, read, seen or experienced. If these resources are inadequate, they seek additional information from other sources. The information may not be acted upon or utilized in any way, but it appears that just having the information provides people with a sense of control and power. The information provided may not need to apply to any specific disease or illness, as Lindner [1] has suggested, but may be of a general nature or may be information regarding wellness or prevention of a disease. Therefore, the scope of the term Information Therapy is expanded beyond disease-specific information, and beyond patient education. The parameters of Information Therapy should include: disease-specific information targeted toward an individual such as the causes, symptomatology, and treatments available for multiple sclerosis; health information on a general topic such as breast cancer or heart disease; or preventive health information targeted to the general public on topics such as smoking cessation, nutrition and vitamins, exercise and wellness issues. Thus, virtually any information dealing in any way with medicine, health, wellness or quality of life that can be informing, increase skills or improve the attitude of a person can be termed Information Therapy.

The coverage of Information Therapy, as should be for all information of any nature, is universal. Healthcare reform policy is concerned with universal access to healthcare, and in the same manner, Information Therapy should be accessible to every individual. Unfortunately, in the past this has not been the case, as Lindner [1] describes that she was unable to deliver information to patients because the "policy" of the medical library where she worked prevented her from giving specific information to patients without their physician's consent. The *President's Commission on Ethical Practices in Medicine* in 1982 has mandated that medical libraries be open to health consumers, and the Medical Library Association's Code of Ethics includes an ethical obligation to advocate access to information for all people.

Information Therapy is meant to increase the general public's knowledge concerning health issues, and should help to create a sense of responsibility in them for their own health. In this way, one of the roles of Information

Therapy is to provide patients with informational services and support that will provide facts and decision-making assistance, which will empower them to manage their health, illness, acute or chronic disease, life-threatening situations, or a loss. The Planetree Health Resource Center, located on the San Francisco campus of California Pacific Medical Center, was founded on the belief that "access to information can empower people and help them to face health and medical challenges." [14] This Resource Center is a medical library which is open to the public and promotes individual responsibility for health through the provision of information. Armed with information, people are able to provide more self-care and to accept self-responsibility for their health and well-being. Pingree et al. states that "for people diagnosed with life-threatening illnesses, obtaining necessary information, making effective plans and decisions, and locating sources of support can play a key role in coping with the crisis." [15]

Another important role Information Therapy can provide to people is assistance with self-care. Levin defines self-care as "an intentional behavior that a lay person takes on his or her own behalf, or on behalf of the family, friends, or community to promote health or to treat illness." [16] The practice of self-care includes a variety of activities such as: self-diagnosis based on previous experience, seeking advice from friends and family, self-medication with over-the-counter medicines and home remedies, consulting books and magazines, asking the advice of pharmacists, or consultation with a healthcare professional. [17] Ferguson [9] proposes a framework for understanding an individual's attempt at self-care and the impact information can have on self-care. This model is shown in Figure 1.

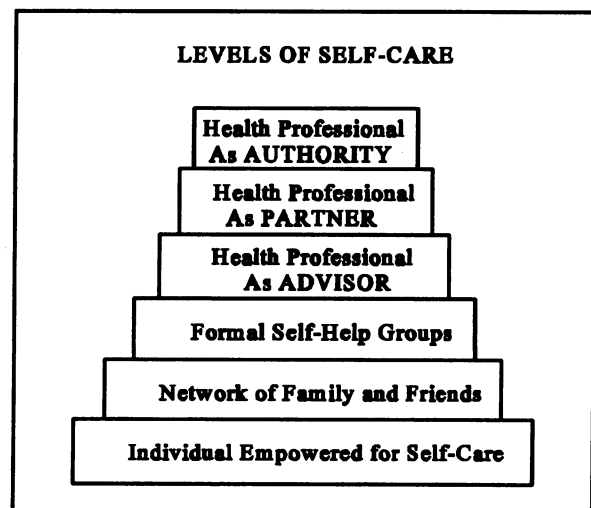


Figure 1 (adapted from Ferguson, *The Futurist*, Jan-Feb, 1992)

The first step is when individuals, before consulting a physician or other healthcare professional, conduct a search for information on how to manage on their own. They utilize self-care, thereby successfully dealing with health problems by providing self-therapy. The next step is when the individual utilizes information from family and friends, thereby successfully dealing with a health problem through therapy given by family members or friends. Next is the level of formal self-help groups, where groups of individuals with similar health problems administer therapy to each other. The fourth step is the initial contact the individual has with a health professional who serves only as an advisor and realizes that with the appropriate information therapy and support, patients can effectively manage their own care. The fifth step utilizes the health professional as a partner, and occurs when the patient and healthcare provider as equal partners decide on an appropriate therapy. The top level utilizes the health professional as an authority, and is when the healthcare provider is the authority who manages the therapy for the patient. According to Ferguson, this top level is appropriate in less than 0.1% of health problems. An Elliott-Binns study [18] of 1,000 patients in an English general practitioner's office concluded that 96% of patients had received advice or treatment before coming to the physician. Most health problems can be handled with therapy in the bottom two or three steps of this framework. Thus, the more Information Therapy people receive, the more active role they can play in their healthcare and can push self-care into one of the bottom levels of the model. This model is not meant to circumvent healthcare providers, but merely to empower people for self-care and free the provider for those whose care must be managed for them. By providing Information Therapy in this way, healthcare costs will decline because people will increase self-care and decrease usage of medical care.

A third role for Information Therapy is to decrease the usage of scarce healthcare resources. Kemper's meta-analysis of the effect medical self-care interventions demonstrated that self-care is in widespread use, and that its use can produce significant effects in terms of utilization of healthcare and reduction of costs.[17] Information Therapy can play a major role in assisting people with self-care, and should be a part of healthcare reform to reduce the costs of medical care.

THE GOALS OF INFORMATION THERAPY

The idea of information becoming therapy may be a new use of the term therapy. However, various departments in a healthcare setting provide therapy to patients: physical therapy, occupational therapy, speech

therapy, etc. Whatever form it takes, the essential purpose of all these departments is to help the patient resume (or maintain) the normal activities of independent living. New uses of the term therapy are also seen in areas such as dance therapy, music therapy, art therapy, vitamin therapy and aroma therapy. While these uses of the term therapy may not fit our traditional definition, their intent is also to help the patient maintain normal activities, oftentimes in the absence of any disease. In this way, information is also seen to provide the patient with the means for self-care when there is an illness, self-help with decision making, and self-wellness in the area of prevention. Brown made this application of bibliotherapy, stating that "reading guidance can be regarded as bibliotherapy even though there is no physical or mental disorder requiring help." [3] Thus, information can be utilized as a therapeutic device, whether for illness or health.

The goals of Information Therapy can be separated into two categories: those that relate to the patient, and those involving medical care. The goals relating to the patient are: (1) to provide people with a sense of control; (2) to provide coping and disease management skills; (3) to improve the capacity to respond; (4) to enhance psychological as well as physiological well-being; and (5) to enable people to provide self-care. These goals, centered on the patient, are of a proactive rather than a reactive stance.

The goals of Information Therapy which apply to medical care are: (1) to enhance the doctor-patient relationship by patients being better informed; (2) to increase patient question-asking, allowing the doctor to provide information therapy; (3) to decrease usage of hospital and physician services by people utilizing self-care; and (4) to prevent costly acute and chronic complications of disease by patients' awareness and self-responsibility.

CONCLUSION

There are several barriers to the widespread use of Information Therapy that must be addressed. These include: the quality of the content of the information; liability and confidentiality issues; a person's ability to filter large amounts of information and determine its usefulness; a needs assessment as to the usability of Information Therapy, both from the patient's point of view and from the healthcare professional's view; and the cost of provision of Information Therapy, including the possibility of third-party reimbursement.

The information superhighways can provide a unique delivery system for Information Therapy. Online

systems, bulletin boards, the Internet, and other systems can provide people with access to health information. In addition, the telephone can utilize information lines that are already in place, and can provide a platform for people to acquire information. More studies are needed to assess the impact of these systems in the delivery of Information Therapy.

The initial usage of the term "information therapy" by Lindner [1] has been expanded in this discussion of a definition for Information Therapy, the role Information Therapy can play in this era of healthcare reform, and the goals that Information Therapy should strive for. The formal definition presented here is that Information Therapy is "the therapeutic provision of information to people for the amelioration of physical and mental health and well-being." Thus, for physicians, medical librarians, healthcare professionals, and indeed anyone, the admonition in the title of Lindner's article[1] still resounds that we should "Encourage Information Therapy".

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